

PIC *Highlights*

Volume 8, No. 2

Spring 1998

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Promoting Safe and Effective Genetic Testing

Genetic testing, although still in its' infancy, has the potential to detect an individual's predisposition to disease and to confirm a suspected genetic alteration in an individual or family. Concerns about the appropriate use of genetic testing led to the formation of the Task Force on Genetic Testing by the National Institutes of Health (NIH)–Department of Energy (DOE) Working Group on Ethical, Legal, and Social Implications (ELSI) of Human Genome Research.

Promoting Safe and Effective Genetic Testing in the United States: Final Report of the Task Force on Genetic Testing, makes policy recommendations that will reduce the likelihood of damaging effects so that we can fully realize the benefits of genetic testing. The Task Force examined the validity and usefulness of the genetic tests, issues of quality assurance related to the laboratories in which these tests will be performed, and the appropriate uses of genetic tests by health care providers and consumers. The importance of informed consent for testing was raised in this regard.

In 1995, the Task Force surveyed organizations likely to be involved in genetic testing in the United States to determine the state-of-the-art in genetic testing. Upon completion of the survey, in-depth interviews were conducted with 29 of the 463 organizations that were either developing or providing genetic tests. Papers were commissioned on some of the more frequent genetic screening programs and information was also

solicited from consumers and professionals on their own personal experiences with genetic screening.

For the most part genetic testing in the United States has successfully provided options for avoiding, preventing, and treating inherited disorders. However, the Task Force identifies the following problems with the current practices of genetic testing: genetic tests are introduced before they are demonstrated to be safe, effective, or useful; laboratories performing genetic tests for clinical purposes lack quality assurance appropriate to such tests; informational materials distributed by the academic and commercial genetic testing laboratories do not provide sufficient information to fill the gaps in health care providers' and patients' understanding of genetic tests. This latter problem could contribute to problems with informed consent. The Task Force anticipates that in the not-so-distant future a greater demand for offering genetic testing will fall on providers who have little formal training or experience in genetic testing.

The Task Force makes several recommendations. Primarily, the Task Force recommends greater oversight of research and clinical uses of genetic testing both in for-profit and in non-profit settings. To that end, the Task Force recommends that for-profit companies be placed under the same guidelines as federally-funded research, which must follow Federal guidelines for ethical review of all projects involving human subjects. Research protocols should be approved by an Institutional Review Board (IRB) when individual identifiers are retained on sample or test results and when the intention is to make the test available for clinical use.

Another recommendation of the Task Force was that the Department of Health and Human Services (DHHS) should establish an advisory committee on genetic testing with representation from stakeholders in the private sector, consumers, and professional societies. The committee would advise the Secretary of DHHS on the implementation of the recommendations made in this report to ensure that the introduction of new

genetic tests for clinical use is based on evidence of their analytical and clinical validity, and utility to those tested; all stages of the genetic testing process in clinical laboratories meet quality standards; health providers who offer and order genetic tests have sufficient competence in genetics and genetic-testing to protect the well-being of their patients; and that there be continued and expanded availability of tests for rare genetic disorders.

Currently, genetic tests are not regulated by any Federal agency, unless they are marketed as a tangible product ("a kit"). A company marketing a service (doctor sends a sample to a biotech company), does not face any regulations. Developing technology will lead to a dramatic increase in DNA testing in the next 5–7 years. Additionally, the Task Force discourages direct advertising or marketing of predictive genetic tests to the public and urges consumers to discuss testing options with a health care provider competent in genetics before having any genetic testing.

The work of the Task Force was supported by the National Human Genome Research Institute at NIH. The report is available on the World Wide Web at http://www.nhgri.nih.gov/ELSI/TFGT_final. Copies of the executive summary of the report, PIC ID No. 6090, are available from the Policy Information Center.

The Well-Being of America's Children and Youth

The report, *Trends in the Well-Being of America's Children and Youth '97*, is the second annual report from the Department of Health and Human Services (DHHS) to present the most recent, reliable data on five key areas in the lives of children and youth. These areas are:

- population, family, and neighborhood;
- economic security;
- health conditions and health care;
- social development, behavioral health, and teen fertility; and
- education and achievement.

The report presents the most recent and reliable estimates on more than 80 indicators of well-being. For each indicator, the report provides one or more graphics to highlight key trends and important population sub-group differences, and tables that provide more detailed information for the interested user. These are accompanied by text which briefly describes the importance of each indicator and highlights the important features of the data.

The report attempts to provide a picture of how youth are faring overall. For example, a selection of findings from the report that relates to the experiences of teenagers finds that:

- The teen birth rate for young women between the ages of 15 and 19 years has been dropping since 1991, with the largest decrease among black teens.
- Following periods of decrease during the previous decade, the use of cigarettes, marijuana, alcohol, and cocaine has increased.
- 17-year-old students have made modest gains in mathematics and science proficiency since the early 1980s.

- The mortality rates for black youths ages 15–19, following a sustained period of decline, increased dramatically during the late 1980s, and has remained at a very high level since 1991. During that same time period, mortality rates among white youth ages 15–19 declined.
- Receipt of early prenatal care by teen mothers has increased steadily during the 1990s.

The report shows that although the data available for tracking the well-being of America's children and youth at the national level are fairly extensive, there remain major gaps in the Federal statistical system if we are to have a complete picture of the quality of our children's lives. For example, there are few measures of social development and health-related behaviors, for very young and pre-teenage children, which are measured on a regular basis. Currently, the Federal statistical system lacks good indicators of school readiness for young children, measures of mental health for children of any age, and positive measures of social development and related behaviors. The result of the latter deficiency being that the current set of indicators may paint a more pessimistic picture of children's well-being than the reality.

New indicators should be developed that reflect the positive developments in the well-being of children and youth. Indicators need to be developed that: reflect important social processes affecting child well-being that go on inside the family and within the community; relate to fathering; provide annual information on whether both biological parents live in the household; and estimate the problem of child homelessness. The report also challenges agencies to improve the quality, consistency, and frequency of available data in other areas, including: child abuse and neglect, youth violent crime, day care quality, learning disabilities, and measures of children in institutionalized care.

This report was sponsored by the Office of the Assistant Secretary for Planning and Evaluation. The report's project officer, Matthew Stagner, may be reached at 202-690-5653. Copies of the intro-

duction to the report, PIC ID No. 6170.1, are available from the Policy Information Center. The entire report is available for purchase at a cost of \$26.00 from the Government Printing Office (stock number: 017-022-01370-3).

Work First and Other Work-Oriented Strategies in Five States

The Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996 replaced the Aid to Families with Dependent Children (AFDC) program and the Job Opportunities and Basic Skills (JOBS) program with the Temporary Assistance for Needy Families (TANF) block grant. This change gave States far greater flexibility to design their own cash assistance and welfare-to-work programs. Individual States are now challenged with translating PRWORA's goal of a work oriented, transitional assistance program into an operational reality.

Building an Employment Focused Welfare System: Work First and Other Work-Oriented Strategies in Five States, reviews the policy choices and experiences of six local sites in five States making the transition from the more traditional welfare focus on cash assistance to an emphasis on employment. The sites chosen for evaluation were: *Indiana*: Indianapolis (pop. 817,604) and Scottsburg (pop. 22,528); *Massachusetts*: Worcester (pop. 718,858); *Oregon*: Portland (pop. 614,104); *Virginia*: Culpepper (pop. 30,528); and *Wisconsin*: Racine (pop. 182,982).

Data used in this report was drawn from site visits to local and State welfare offices between January and March of 1997. Discussions were held with: (1) State welfare administrators and/or senior program staff; (2) local welfare administrators and front-line eligibility and welfare-to-work staff; (3) staff from relevant local agencies, such as employment and training supervisors; and (4)

employers participating in subsidized employment programs or unpaid work experience programs.

The sites were chosen because of the diversity of their approaches to increase employment among welfare recipients. Although the States vary in the cash assistance that they offer, all five States have caseload declines that are well above average, low unemployment, and strong economies. All of the States in the study have also implemented Work First programs which emphasize immediate job search over long-term education and training.

Among the selected programs there are two distinct Work First models in place. The models differ primarily in their consequences for recipients who do not obtain employment after a specific period of time. The Work First, Work Mandate model (exemplified by Massachusetts and Virginia) mandates employment participation as a requirement for continuing to receive cash assistance after only 2–3 months of initial receipt of benefits. The Work First, Participation Mandate model (exemplified by Oregon, Indiana, and Wisconsin) includes job search, and work-oriented education and training as allowable forms of participation throughout the period of cash receipt.

The study identifies key strategies that go beyond the Work First approach to shift to a more work oriented system. These include:

- **Fewer exemptions** from required participation in welfare-to-work program activities and rules
- **More stringent sanctions** for noncompliance with work program mandates to reinforce the importance of employment
- **Diversion efforts** including one-time cash payments; pursuance of alternative resources and applicant job search requirements to discourage families for applying for cash assistance if they have alternative sources of support

- **More generous earned income disregards** to reward recipients' efforts to work, especially if they can only find part-time or low-wage work
- **Time limits** on the receipt of cash assistance to encourage recipients to seek employment as quickly as possible
- **Organizational changes** including shifting more (or all) responsibility for program management and management and operations to Workforce Development agencies, devolving more responsibility to local offices, relying more on performance-based contracts, and changing the roles and responsibilities of eligibility and welfare-to-work staff

This report demonstrates that States have the ability to reconfigure welfare and make new assumptions about what should and can be expected of recipients. All study sites succeeded in restructuring their programs to emphasize employment and to get participants into work activities quickly. However, many participants were still receiving welfare after one year, suggesting that a Work First approach alone is not enough to help all participants achieve self-sufficiency.

This report was sponsored by the Office of Assistant Secretary for Planning and Evaluation. The report's project officer, Elizabeth Lower-Basch, may be reached at 202-690-6808. Copies of the executive summary of the report, PIC ID No. 6227, may be obtained from the Policy Information Center.

Evaluation of Dental Treatment and Health Status Differences Attributable to Water Fluoridation

Despite what many Americans believe, dental caries (tooth decay) remains a prevalent disease that affects people of all ages. But as prevalent as it is, it is also a disease that is preventable. Public health officials have known for more than 50 years that water containing fluoride at a level of 0.7–1.2 mg/L reduces the occurrence of dental caries. *Healthy People 2000* established a goal of increasing to at least 75 percent the proportion of people served by community water systems who receive optimal levels of fluoride. However, as the use of other fluoride products (such as toothpaste, rinses, and tablets) has increased, the observed differences in caries prevalence between children residing in fluoridated (F) and in nonfluoridated (NF) communities have declined.

Final Report: Evaluation of Dental Treatment and Health Status Differences Attributable to Water Fluoridation, presents findings from a study of the effects of water fluoridation on dental treatment experience of persons who had a variety of personal and professional preventive methods available. The study provides data that can be used to assess the cost-effectiveness of water fluoridation and other methods of fluoride delivery, as they were provided in a community setting.

This study used 6 years of data (1990–1995) to assess whether the dental treatment experiences of children and adult members of a group-model dental health maintenance organization (HMO) differ for those with access to fluoridated water and those without. The research setting for this project was the Kaiser Permanente, Northwest Division (KPNW), serving members in Northwest Oregon and Southwest Washington.

Among these members of a group-model HMO, the mean income was high (\$40,000–50,000 per year) and 40 percent were at least college graduates. These socioeconomic characteristics are associated with regular dental care utilization and

effective self-care practices. In spite of these shared advantages, members in the fluoridated communities had lower restorative and total treatment cost—the effect was statistically significant but small. These findings offer reassurance that water fluoridation remains a good investment, even though multiple sources of fluoride are currently available.

Of concern was the finding that, in one of the fluoridated communities, for 4 of the 6 years, more than one-half of the time, residents had received water with less than one-half of the recommended fluoride levels. This finding suggests the need for renewed quality assurance efforts, and for including actual, observed fluoride levels as part of any research protocol assessing outcomes of water fluoridation.

This report was sponsored by the Centers for Disease Control and Prevention. The report's project officer, Dr. Dolores Malvitz, may be reached at 770-488-6055. Copies of the executive summary of the report, PIC ID No. 6334, may be obtained from the Policy Information Center.

National Estimates on the Number and Cost of Immigrants on Medicaid

Prior to the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996, immigrants were eligible for the same Medicaid benefits as U.S. citizens and illegal aliens were eligible only for emergency health care. Under the new welfare reform law, with certain exceptions, aliens who entered the U.S. after August 1996 are no longer eligible for coverage under the Medicaid program for their first five years in the country, but are still eligible for emergency services. Measuring the potential impact of this change has been difficult because there is little data about the number and cost of immigrants on Medicaid to use as a baseline for assessing changes.

This report, *The Number and Cost of Immigrants on Medicaid: National and State Estimates*, provides national and State-by-State estimates of the number and cost of noncitizens receiving Medicaid benefits in 1994.

Data was analyzed from the Medicaid Quality Control (QC) data base for the first half of 1994, with additional information about Supplemental Security Income (SSI) participants from the Social Security Administration (SSA). The QC data base includes verified data for about 93,000 sampled Medicaid enrollees, roughly 2,000 per State, making it the largest known national sample of Medicaid beneficiaries. In 31 States the QC sample excludes SSI recipients and SSA data were used to supplement information about elderly and disabled immigrants.

The report finds that during the course of 1994, 3.2 million immigrants were enrolled in Medicaid. This is less than one might expect given that—according to the 1996 Current Population Survey—12.6 percent of the population under poverty are noncitizens. Adult and aged beneficiaries were more likely to be immigrants than were children or the disabled. The low percentage of child beneficiaries is largely due to the fact that immigrants' children are often native born citizens. The total Medicaid expenditures for noncitizens in 1994 was \$8.1 billion or 6.9 percent of total expenditures.

This paper deals with information collected in 1994 and it is difficult to predict what the future impact of these changes will be. Much will depend on the rate of immigration and the composition of newly arrived immigrants, both of which will be affected by newly enacted immigration policies. The policy choices that States make on coverage for noncitizens will also be very important. Additionally, there may be an increase in the number of immigrants seeking naturalization due, in part, to apprehension about welfare reform. Once the immigrants are naturalized they will be eligible for Medicaid benefits on the same basis as all other citizens. The future cost of increasing the number of low-income immigrants without Medicaid remains to be seen.

This report was sponsored by the Office of the Assistant Secretary for Planning and Evaluation. The report's project officers, David Nielsen and Linda Sanches, may be reached at 202-401-6642 and 202-690-7233, respectively. Copies of the executive summary of the report, PIC ID No. 6791, are available from the Policy Information Center.

New Demand for Information on Program Results

Congressional and agency decisionmakers need evaluation information on Federal programs in order to manage programs effectively, as well as to decide how to allocate limited Federal resources. In the past there has been little formal accountability for government programs. However, beginning in the year 2000, the Government Performance and Results Act of 1993 (GPRA) will require government agencies to report on their results in achieving their agency and program goals. In their past surveys of program evaluation, the General Accounting Office (GAO) found limited and diminishing resources spent on program evaluation.

This report, *Program Evaluation: Agencies Challenged by New Demand for Information on Program Results*, identifies the problem of diminishing Federal resources and responsibility and investigates how Federal agencies can support additional requests for program evaluation information in this environment.

The review was conducted between May 1996 and July 1997. Data was collected from surveys distributed in 13 cabinet level departments and 10 independent executive agencies within the Federal Government. Each office was asked about the range of its analytic and evaluation activities and about the length, cost, purpose, and other characteristics of the program evaluation studies they conducted during fiscal year (FY) 1995.

The report finds that in their current configuration, existing government evaluation resources are likely to be challenged to meet the increasing demand for information about program results. Agencies surveyed identified the resources involved in assessing their programs' results at \$194 million and 669 full-time equivalent staff for FY 1995. These resources were unevenly distributed across agencies. Agencies also reported that the primary role of program evaluation was internally-focused on program improvement, rather than a response to direct congressional or other external oversight.

The report recommends targeting and leveraging Federal and non-Federal resources. GAO suggests that some possible ways to do this include: (1) assisting program managers in the development of valid and reliable performance reporting under GPRA; and (2) planning evaluation studies to fill the most important information gaps—such as providing supplemental information on the reasons for observed performance or examining policy issues that extend beyond program borders. Another way of ensuring that the results of diverse evaluation activities are synthesized to portray programs at the national level is for Federal evaluation staff to coordinate those activities in advance.

This report was sponsored by the General Accounting Office. For more information visit their World Wide Web site at <http://www.gao.gov>. Copies of the introduction to the report, PIC ID No. 6908, are available from the Policy Information Center.

RECENTLY ACQUIRED REPORTS

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(PIC ID No. 6905)
- *Ancillary Services to Support Welfare to Work*
(PIC ID No. 6740)
- *Aid to Families with Dependent Children: The Baseline*
(PIC ID No. 6944)
- *The Dynamics of the Food Stamp Program*
(PIC ID No. 6952)
- *Evaluation of Training for Staff of Childhood Lead Poisoning Prevention (CLPP) Programs, in Light of CDC Revised Policy and Program Priorities*
(PIC ID No. 6663)

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